**Bioethics Case Study 1:**

**Family disclosure – beneficence *vs.* maleficence**

(adapted from Ormond, 2008)

A woman with a family history of Huntington’s disease (HD) wants to undergo genetic testing to determine her risk for developing this adult onset autosomal dominant neurological disorder. Her paternal grandmother had HD; this means that there is a 50% risk that her father inherited the mutant HD allele, and that she has a 25% risk for having the mutant HD allele. A negative result would mean that the woman is not at risk for HD, but would not provide information about her father’s risk. However, a positive result would mean that the woman has inherited the mutant HD allele, which means her father also has the mutation. Complicating matters even further is the fact that the woman has a brother who has recently had a baby; this brother does not know about the family history of Huntington’s disease. There is currently no treatment for Huntington’s disease.

1. How does this case challenge the traditional medical paradigm that medical information is individual?
2. Whose right for obtaining information takes precedent – the woman, who wants to know if she will develop HD, or her father, who does not want to know if he will develop HD? Explain your answer.
3. Are any of the individuals involved obliged to tell the brother about his at-risk status? Explain your answer.
4. Would your answers to these questions change if treatment for Huntington’s disease were available? Explain your answer.

**Bioethics Case Study 2:**

**Gene therapy vs. gene enhancement**

(adapted from NOVA)

In this theoretical case study, a mammalian gene has been identified that functions to increase capacity for learning and memory, essentially increasing IQ. Average human IQ is 100; an IQ of 70 or less is considered an indication of mental disability. The introduction of this learning & memory gene has the potential to increase human IQ by 30 points. A couple has a 5 year-old son with Down syndrome whose IQ is 70. This couple wants to use this technology to increase their son’s IQ from 70 to 100; this is considered gene therapy, because the technology would help an individual with a disability function better. A second couple has a 5 year-old son with an IQ of 120. They want to use this technology to increase their son’s IQ to 150, as they think this will help him be more successful in the future; this is considered gene enhancement, because the technology would be used to enhance a characteristic in an individual who already functions at a normal or above normal level.

1. Should gene technology be used for gene therapy? Why or why not? Discuss an example in support of your argument.
2. Should gene technology be used for gene enhancement? Why or why not? Discuss an example in support of your argument.
3. Why is the line between gene therapy *vs*. gene enhancement “blurry”?
4. Who is responsible for making the decision about whether this technology should be used? Parents? Doctors? Government? Society? Other? Explain your answer.